

Bill 5009

NATIONAL
MARROW
DONOR
PROGRAM®

The Honorable Joseph J. Crisco, Co-Chair
Connecticut State Senate
The Honorable Steve Fontana, Co-Chair
Connecticut General Assembly
Insurance and Real Estate Committee
Room 2800, Legislative Office Building
Hartford, CT 06106

February 11, 2010

Re: Letter of Support—Insurance Coverage Testing for Bone Marrow Testing

Dear Senator Crisco and Representative Fontana:

Every year, more than 10,000 Americans are diagnosed with life-threatening diseases such as leukemia or lymphoma. Because most patients (about 70 percent) in need of a transplant do not have a matching donor in their family, they look to the National Marrow Donor Program for an unrelated donor or cord blood unit for a transplant to potentially save their life.

The National Marrow Donor Program is the international leader in bone marrow and cord blood transplantation. For over 20 years, the NMDP has facilitated over 40,000 transplants for patients with blood disorders such as leukemia, lymphoma, and aplastic anemia, as well as certain immune system and genetic disorders. Our organization recruits marrow donors in communities across the country on behalf of searching patients in need of a transplant. The initial steps of that process is the typing your bill supports which is testing for matched donors based on human leukocyte antigens (HLA) typing. This special typing is important in matching patients and donors for a marrow or blood stem cell transplant.

We support your bill because it will allow more individuals who wish to join the registry the option to cover the costs of their initial tissue typing. Currently the total costs to add a new member to the Registry is about \$100. This includes the cost of the testing needed to match donors to searching patients and related costs. The NMDP receives limited funding from the federal government to cover some tissue typing costs. Our foundation also helps to raise funds to cover costs of initial HLA testing; however, there is not always enough to cover the number of donors needed, so sometimes new members are asked to make a donation to defray costs of joining the Registry. Your bill would help fill the costs gaps to add more individuals to the registry. It should be noted that once a potential donor joins the registry, that if they become a match for searching patients, there is still no cost to them to donate--the patients insurance covers costs related to the

donation of marrow. In essence, your draft legislation will help meet a growing need to add more donors to the registry as more and more patients each year are in need of a transplant.

If passed, Connecticut would join several states (Massachusetts, Missouri, New Hampshire) that require insurance coverage for HLA typing. As more states begin allow insurance coverage to the initial costs of typing, we hope that it will allow more individuals to join the registry.

We strongly support your proposal, and we hope that the legislature will pass this bill. Thank you for considering our letter, we want to work with your offices, the legislature and our advocates in Connecticut in any way possible to enact this law. If you have any questions, or need any additional information from the National Marrow Donor Program, please don't hesitate to contact me directly via email at mspencer@nmdp.org or 202.636.8668.

Sincerely,

Maria Spencer

Maria D. Spencer, Director
Legislative Relations